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India

Grassroots HIV/AIDS Activism Growing

Manju Parikh, Associate Professor, College of Saint Benedict and Saint John's University, MN, August 17, 2006

"In the past few weeks, India has made headlines for two very different reasons. The good news was that India's economy grew at the fastest pace in more than two years, surpassed only by China. The bad news soon followed, however. India has overtaken South Africa as the country with the highest number of people living with HIV/AIDS, according to the latest figures from the Joint U.N. Program on HIV/AIDS." *The Lancet*, June 10, 2006.

"A new U.N. report in has warned that the country's booming economic growth could slow if HIV/AIDS continues to spread unchecked. The United Nations says 5.7 million people are infected with HIV in India — the largest number in any country in the world. The report says the potential economic costs of HIV/AIDS in India could be huge, cutting economic growth by close to one percent over the next 10-15 years." *OneWorld South Asia*, July 26, 2006.

In the last ten years, we have seen frequent news reports on the spread of the HIV/AIDS virus in the Indian subcontinent, each one stressing the dire economic and social consequences if urgent attention is not paid to the problem. Although the Indian government has responded by adopting many policies and by establishing an organization — the National Aids Control Organization (NACO) — to deal specifically with HIV awareness, treatment for HIV infected individuals, and prevention of further spread of HIV/AIDS, many critics do not find these measures adequate.

The campaign to create awareness and check the spread of AIDS is a mammoth enterprise which involves collaboration between various institutions of the Indian government at national, state and local levels, along with international organizations such as the United Nations Development Program (UNDP), the World Health Organization (WHO), as well as major private foundations from abroad (Gates Foundation, Bill Clinton Foundation, Elton John AIDS Foundation) in addition to local non-governmental organizations (NGOs), and civil society institutions. Macro-level focus on the problem of HIV/AIDS in India is useful for highlighting the gravity of the problem and for evaluating its progress. However, we might also benefit by looking at the issue from the micro level — that is, through the grassroots efforts of various NGOs, and through the experiences of individuals coping with HIV/AIDS.

The reflections that follow offer a window into the quiet but major changes in social values and attitudes now taking place in Indian society as a result of its encounter with HIV/AIDS. It is easy to become pessimistic when we focus on the scale of HIV/AIDS infection in India. This journey into the activities of individuals and organizations engaged in raising awareness, empowering HIV infected persons, and stopping its further spread offers some glimmers of hope.

My recent but incidental foray into the activities of a few organizations and individuals involved with HIV/AIDS Awareness and Prevention Campaign in Kolkata produced at first amazement, but also much admiration and appreciation of their efforts and accomplishments. Although my short visit did not allow me to do an exhaustive survey and research, I learned enough to be able to go beyond the bleak picture frequently portrayed in the media. I am not questioning the seriousness of the situation in India with 5.2 million estimated cases of HIV infections (the Indian government estimates are lower than the U.N. figure of 5.7 million cases). However, I felt that I needed to see beyond the macro level to get a more nuanced picture. My conversations with activists, and research into the grassroots organizations in Kolkata allowed me to appreciate the immense creativity in the responses involved in dealing with the HIV/AIDS challenge. More

importantly, I could detect a quiet social revolution taking place in a very traditional society which does not favor public discussion of topics related to sex and sexuality.

My journey began with an invitation to attend a workshop on HIV/AIDS Awareness on June 10 hosted by the Sukriti Foundation and the Lions' International Club of Kolkata (District 322 B 1). It was an eye opener on so many levels. The majority of the audience consisted of young men and women (from schools and colleges), who had voluntarily signed up to participate in the workshop. I was pleasantly surprised to hear a representative from the West Bengal State AIDS Prevention and Control Society (WBSAP&CS) speak openly about the increasing spread of the HIV/AIDS in the state and discuss the government's strategy for its control and further prevention. Then Dr. Basudev Mandal, a physician and District Governor of the Lions' Club, talked frankly about the different forms of transmission and means of prevention. Next, the audience heard from Samit Biswas, a HIV+ activist, who spoke about the difficulties he had encountered in receiving medical help and support from his family because of their lack of knowledge about the nature of this infection. In addition, we also heard from a few female sex workers who talked about the difficulty of persuading their clients (often young males) to use condoms. As the workshop progressed, two young women organizers rallied the participants to volunteer for a program to visit schools where principals and teachers have been reluctant to allow sex education and discussion of HIV/AIDS infection and prevention.

Such open public discussion of sex and consequences of unprotected sex related were a big surprise to me. Indian society still upholds very conservative values (a legacy of British rule) and public conversations about sex are still a taboo in most families. Indeed, until recently, middle class Indians tended to associate HIV/AIDS only with prostitutes, truck drivers, drug users, and poor migrant workers, etc. and devalued their health problems by attributing them to their 'immoral conduct.' However, the wake up call came in studies which showed the increasing spread of the infection in the general population and especially, in the age group of 15 to 49 years. In fact, Indian youth are considered the most vulnerable group. This explained the focus on the youth in the workshop I attended.

The Sukriti Foundation is a non-governmental organization that is affiliated with the Sukriti TV channel, which focuses on health and education in its public affairs programs. In 2005, the Foundation focused on the HIV/AIDS campaign with the aim of increasing social awareness on its basics as there was a great deal of misinformation about its spread. They had live interviews with health professions and social workers to provide accurate information about HIV/AIDS. They also invited HIV+ persons to talk about their experiences, which highlighted the discrimination they faced, along with ill treatment by medical professionals, neighbors, and even family members. The majority of the India public lacks basic knowledge about the nature of HIV/AIDS infection.

One of the goals of the Sukriti Foundation was to empower HIV+ persons by showing solidarity and support. With this goal, they organized "Reach out," a youth campaign event, with a rock concert featuring Fossils, a leading band in Kolkata. The success of the event was demonstrated by the fact that the show was completely sold out. What was remarkable was that not only were HIV+ persons allowed to speak about their painful experiences of being socially ostracized and mistreated, but the courage they displayed to come out publicly and acknowledge their HIV+ status. The event was dedicated to "Dola," a young schoolgirl who had faced awful mistreatment because of her mother's HIV+ status. The rousing finale of the event was a song, "You are not alone, we are with you," by a popular singer, Usha Uthup, which produced a spontaneous collective echo from the audience. As I saw the photos of the event and heard about it, I came away feeling that Indian society had begun to recognize that it was truly unfair to discriminate against children and wives of HIV+ men, and that HIV+ males themselves should be treated with dignity as human beings and with respect as citizens in a democracy.

Of course, it is easy to brush aside this rock concert as a minor event when one finds more stories of HIV/AIDS infected persons' experiences of abuse, ill treatment and neglect by health professionals and public officials in the media. At the same time, we would be ignoring certain important changes in social attitudes taking place if by failing to acknowledge that events, expressing solidarity with HIV+ individuals, are taking place more frequently and in a variety of locales and formats in Kolkata. For instance, the city recently had two international AIDS Candlelight Memorials to honor the lives of those lost through AIDS. These AIDS memorials brought together various NGOs who are involved with the HIV/AIDS Awareness and Prevention Campaign. The gatherings included dance performances, sharing life stories of struggle and survival, panel discussions on issues of child sex-workers, drug abuse, rights of sexual minorities, and gender and sexuality in Indian society. At the International AIDS Candlelight Memorial organized by the

WBSAP&CS, the guests included the Mayor of Kolkata, and the U.S. Consul General. At this gathering as well, several individuals living with HIV/AIDS belonging to the Bengal Network for People Living with HIV/AIDS and the Kolkata Network of HIV Positives spoke about their life experiences.

In June, Kolkata also had a celebration of Pride week, an event that has been taking place yearly since 2003. Among the activities of the week was a Gay pride parade, "Walk on the Rainbow," (which is supported by an increasing number of organizations), cultural performances and discussions on human rights protections and legal reforms — especially the need to remove Indian Criminal Code, Section 377 (a form of sodomy law), which is used by police to harass gay men.

The WBSAP&CS is a quasi-governmental organization which works with private sector and non-governmental organizations to promote awareness of HIV/AIDS, provide support for HIV infected persons, and to prevent the spread of infection. Its guidelines are from the National AIDS Control Organization (NACO), and its mission is to "empower people in West Bengal to make informed choices in relation to HIV/AIDS prevention, care, support, and treatment through a combination of innovative communication strategies and provision of quality health services."

Through results collected from recent surveys, the WBSAP&CS has observed that the state is experiencing an unexpected increase in the number of HIV/AIDS cases. Although it was considered one of the low-prevalence States compared to others in India, WBSAP&CS acknowledged that the epidemic was now spreading to the general population and was no longer restricted to most at-risk populations (prostitutes, truck drivers, migrant workers, and intravenous drug users). Unprotected sex (male to female, and male to male) was the primary route of transmission, accounting for 89 percent of the infections. Furthermore, the concern was greater for youths between the ages of 15 and 19 who are vulnerable and very susceptible to HIV infection because their interest in sexual experimentation and engagement in unsafe sexual practices without the necessary information on sexually transmitted infections (STI) or HIV/AIDS infection, and ways to have safer sex. High prevalence of STIs also makes the population more susceptible to HIV infection.

Recognizing the seriousness of the problem, and the need to reach a vast population (with a high percentage of illiteracy) in a rapid and effective way, the state launched a mass communication campaign through use of an animated character called Bula di (elder sister Bula), as an icon to lead the fight against the HIV/AIDS infection. What makes her appealing is that she appears as a pragmatic and informed sister/community social worker or neighbor next door who offers counsel and advice on safe sex. In two years, Bula di has become a familiar figure being seen in numerous TV spots, radio jingles, print media and billboards offering practical advice. In Kolkata, her image is ubiquitous — she is at bus stops, at major traffic intersections, at neighborhood soccer matches, at community gatherings, at Pujas (religious festivals and celebrations), at race tracks, and discotheques. The public is encouraged to call a hotline number (1097) to speak to a counselor who can answer HIV/AIDS-related queries.

The Bula di campaign's messages are geared toward removing the public's anxiety and misconceptions about the spread of HIV/AIDS. Gingerly at first, she tackled the dilemma of the widespread prevalence of STDs. Bula di's advice was, "What everyone should know about STDs, Protection is Prevention." From there, she moved on to encouraging voluntary HIV tests and then to promotion of the use of condoms for safe sex. Here are some examples from billboards: "But, Bula di, won't using a condom mean suspecting my partner?" Bula di responds, "Not at all. Rather it is a sign of a healthy relationship." Below the two figures is the primary message: "Unprotected sex can cause AIDS." In another billboard, a worried housewife who knows about her husband's infidelity and wonders if she should overlook it, is advised, "Go for a blood test immediately."

Some critics questioned the 'gender bias' in the campaign which seemed to be reaching out more to women. There were good reasons for this focus at the outset; women constitute about half of all persons living with HIV/AIDS in the world. In India, 38 percent of adult HIV/AIDS cases are women, and in West Bengal, 61 percent of all infected women were married, and the majority were in monogamous relationships. Pre-campaign surveys had also shown that a large percent of rural and urban women were poorly informed about the source of transmission of HIV, did not think that they could get infected, and had many misconceptions about condoms.

Recently, the Bula di campaign has irked some folks for actively promoting condom use. Here are some samples messages: "Have fun responsibly, always carry condoms," "You might have the urge any time: always carry condoms," or, "Only condoms ensure a healthy sex life." These messages also have an accompanying reminder that "Condoms are the best way of preventing HIV/AIDS infection." Some parents, teachers, and women's groups criticized the sexually explicit language in the ads and radio jingles. Some school principals have complained that its messages may encourage young people to engage in sex. The state government has urged WBSAP&CS to modify the explicit language in some of its messages, such as "amod ullash korun, kintu condom rakhun," which when translated means "have the pleasure of sex but use a condom."

Using mass communication, the Bula di campaign has reached a large audience, but it is also easy for its messages to be perceived as inappropriate for specific segments of society, such as young children. The challenge for WBSAP&CS is considerable. Faced with the increasing spread of infection, there is an urgent need to educate the public as quickly as possible on the sources of HIV/AIDS transmission and the means of precaution, but on the other hand the campaign also incurs hostility and rejection by the community which still would rather not acknowledge the prevalence of extramarital and casual sex practiced by men and women, and by men with other men, whether young or old, single or married, and rural or urban.

One valid criticism of the Bula di campaign is that it is found primarily in the urban areas, but the infection is now spreading to villages because of migrant labor. Billboards are not as prevalent in the rural areas, which are less literate, and not every village family has access to a TV. Bula di's voice on the radio in the rural areas does not resonate with the mascot's image in a blue sari which residents of Kolkata are used to seeing everywhere.

Recognizing the limitations of the Bula di campaign, several NGOs have taken the lead in reaching the rural population, in cooperation with WBSAP&CS. Prominent among them is the Bengal Network for People Living with HIV/AIDS (BNP+). However, the most energetic group of activists are the People living with HIV/AIDS (referred to by NGOs as PLWHA), who have undertaken the task of monitoring and counseling HIV+ individuals on treatment as well dealing with the bureaucracy. Many migrant workers return to their villages sick with the infection. Isolated in the villages without adequate medical care, they often try to hide their HIV+ condition to avoid the stigma and discrimination. Here is where the BNP+ steps in. They are often in the forefront of fighting back against prejudice and misinformation about the infection and educating the rural citizens on the modes of transmission and mechanisms of prevention.

A lot still needs to be done for the PLWHA, their wives and the children. Too frequently the wives discover their HIV+ status only when their husbands are severely ill or dying. The widows have to endure a lot of hardships with the loss of family's income, and also have to deal with their own, and their children's HIV+ status. If these individuals have learned to cope and obtain necessary medical support, it is because of the leadership of individuals like Samit Biswas, an activist who has organized the HIV+ community in Kolkata and pressured the government to provide the needed support and services. The visible empowerment of the PLWHA in India is the most heartening aspect of this campaign. These individuals have learned to fight India's unresponsive bureaucratic system and demand their rights. They have formed their own national networks (INP+ — Indian Network of HIV+ persons), and have become articulate speakers at public gatherings advocating for their concerns.

Solidarity and Action Against The HIV Infection in India (SAATHII) is another organization which has played a prominent leadership role in the fight against HIV/AIDS through capacity building; networking with various Indian and international AIDS organizations, private foundations, and Indian governmental agencies; training and offering technical assistance; conducting workshops for healthcare personnel and NGO staff members; and managing disseminated information through its electronic listserv (saathii@yahoogroups.com), an online resource center (www.saathii.org), and an HIV/AIDS Services directory (Red Ribbon Pages). It participates in HIV/AIDS forums involving political leaders in drafting HIV/AIDS related legislation, campaigns for reform of laws concerning sexual behaviors/preferences, and plays a major advocacy role for universal access to HIV/AIDS prevention, treatment, care, and support services.

SAATHII has supported cultural performances to sensitize the public on the plight of people living with HIV/AIDS. Other activities such as the Pride Week and annual gay film festivals have also raised public awareness of the discrimination experienced by sexual minorities. The organization has been a champion for

the rights of segments of the society impacted by HIV/AIDS, such as women and children, intravenous drug users, and men who have sex with men (MSM), a broad label which includes a variety of male sexual encounters, not limited to those of self-identified gay men.

Indeed, one of the most important byproducts of the HIV/AIDS campaign has been the gradual societal acknowledgement of the existence of sexual minorities in India. Until recently, the Indian news media tended to portray gay and lesbian movements as restricted to small urban groups which were products of Western influence, assuming that heterosexuality was the dominant sexual norm and practice in Indian society. However, the spread of the HIV/AIDS infection and results of several surveys have unquestionably revealed that along with heterosexual relations, homosexual and bisexual practices are commonly found in both rural as well as urban contexts, and among the poor, low and middle income strata, as well as the Westernized elite.

When HIV/AIDS first became a public concern in India, the official response was to identify and target 'high risk groups' for intervention such as prostitutes, intravenous drug users, truck drivers. However, this strategy has now proved to be inadequate in preventing the spread of the HIV infection because it did not deal with the broad range of Indian male sexual behavior, which would encompass extramarital sex, homosexual relations, as well as bisexual exchanges (men who are married but also have male partners).

A visitor to India is often struck by the public display of affection between men. Shivananda Khan, a scholar and activist, has explained that the dominance of men in public space and their ability to express affinity to other males, have facilitated male to male sexual relations which are based on specific, culturally defined 'gendered self-identities' and sex roles. In other words, some men are attributed with or have taken 'a feminized self-identity' to describe their sexual behavior with other men. They are often called "Kothis," and distinguish themselves from their male partners by their 'gender identity' rather than 'sexual identity.' Importantly, they do not like being called homosexuals; they perceive themselves as behaving 'not as men' with other men.

Such 'gendered' relations between men are commonly found among low income, rural and urban populations, where there is poverty, low levels of literacy, and sexual segregation. In addition, there also exists a community of hijras — castrated men who cross-dress as females and earn a living as commercial sex partners for men. Regardless of these men's predilection for sex with other men, South Asian culture demands that all men should be married to women, so many MSM, of whichever gender identification or sexual orientation, are either married or do plan to marry. Many are engaged in sexual relationships with men and women simultaneously. It is important to note that in the South Asian patriarchal culture, where men have the privileged position of dominance, most MSM would not publicly acknowledge their sexual behavior out of anxiety over public shame and fear of loss of honor as a male.

These distinctions are significant because 'gay' as a category does not cover the varied male sexual practices that are found in South Asia. The word has only been adopted as an identity by a small percentage of urban, English-speaking, affluent men. If HIV prevention efforts were limited to only the gay-identified population, a large section of the MSM community would be left out. One important contribution of Indian NGOs has been to question the validity of the western model of HIV intervention in the Indian context, where gay identified groups are small.

By focusing on the varied sexual relationships and practices of men in the South Asian context, organizations such as SAATHII and the Naz Foundation in New Delhi have also underlined the need to go beyond the high risk groups to include the MSM in order to prevent further spread of HIV/AIDS. Through their workshops and resource materials, these organizations have helped to educate health professionals, social workers, and governmental officials to broaden the scope of their efforts at HIV/AIDS prevention.

In conclusion, my short but very fruitful association with these organizations made me see a silver lining in the large, dark cloud of HIV/AIDS in India. I feel that the HIV/AIDS Awareness and Prevention Campaign has allowed several marginalized and discriminated groups (PLWHA, female sex workers, MSM and, other sexual minorities) to be organized and to demand their rights and appropriate services for their condition. Their empowerment is definitely a positive development. Secondly, SAATHII and other MSM organizations have been articulate in advocating a model of HIV prevention activities appropriate for the Indian context, highlighting that men engaged in sex with other men are not a homogenous group. Furthermore, if these men were not reached by intervention efforts, HIV would spread further and rapidly. Finally, the gravity of

the Indian HIV/AIDS situation cannot be denied. However, I feel that it is important to acknowledge the activities of grassroots organizations and civil society groups which are ushering in profound changes in social values and attitudes in India, and in the long run, their activities will have a definite and important impact on the future spread or control of HIV/AIDS in India.

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